

~ Special Commission on Ovarian Cancer ~
DPH Lobby 2 Conference Room
November 8th, 2016
Meeting Minutes

Commission members present: Dr. Michael Birrer, Joyce Kulhawik, Kate Martin, Dr. Ursula Matulonis, Undersecretary Alice Moore, Betsy Neisner, Lea Susan Ojamaa, Katiusia Potier, Diane Riche, Elaine Zollo

Staff/consultant support: Lilly Benham, DPH, Allison Hackbarth and Emily Breuer, JSI

Meeting started with welcome, introductions and approval of the last meetings minutes. Lea Susan Ojamaa, DPH, chaired the meeting.

Meeting agenda consisted of: a review and discussion of the report outline; possible recommendations; a discussion of information gathered since first meeting; and addressing unmet needs.

A review and discussion of the report outline:

Group was reminded that DPH has engaged JSI as a consultant to write the required report on behalf of the Commission. Allison Hackbarth, JSI reviewed proposed outline and received feedback/input from Commission members.

Section I will focus on the landscape of ovarian cancer. Group would like the unique factors of ovarian cancer noted, i.e., higher stage at diagnosis; frequently diagnosed by a gynecologist rather than a gynecological oncologist; and as diagnosis is often in a later stage, the psychosocial needs can be greater. Group also would include statistics/data in this section, not just narrative. Group is interested in trends in MA, particularly for stage at diagnosis. JSI to research.

Group recommended definitions of stages to be included with a tangible explanation of what it means for people diagnosed at each stage. Section needs to speak to the journey for ovarian cancer patients and survivors, and the care needed through post diagnosis. Report should connect landscape to recommendations, and possibly include an appendix with additional information.

Section II will address the charges of the Commission and recommendations for each. Charge 2 is to effectuate early diagnosis and treatment. Commission feels it is important to address diagnosis and treatment separately and not as one. Commission members are focusing on prioritization of recommendations, rather than a large number.

Possible recommendations:

Commission members had a preliminary discussion about recommendations to be included in the report. Screening and improved education were the two main focuses in crafting possible

recommendations. Group discussed data collection, education of physicians, and physicians' interaction with patients. This conversation will be discussed more fully at the next meeting as we review draft of report.

Information gathered since first meeting:

At our first meeting, various items were raised for JSI to look into at the group's request. Included were trends in data, age-related mortality rates, genetics/screening, symptoms, risk factors, age groupings for data analysis, and disparities. Allison Hackbarth presented results of research to date.

Unmet needs:

Commission continued a discussion from first meeting about addressing unmet needs. Group voiced a range of unmet needs to be considered for inclusion in the report. Examples included: unique needs vary by age; psychosocial support for patients and families is needed from diagnosis to survivorship; support for how to have children or a family after a hysterectomy; and educational programs to raise awareness about symptoms for women, families, and physicians. Financial issues, hospice, access to comprehensive care, and participation in clinical trials were also identified as unmet needs. JSI will conduct a literature search on what national organizations have determined are best practices and successful strategies, and if any of those resources are available in Massachusetts. Dr. Birrer will also collect information on high-level unmet needs.

Next steps:

JSI will prepare a draft report in advance of our next meeting. To continue to inform the report, JSI will conduct key informant interviews with Commission members. Commission members will receive a draft of the report in advance of our next scheduled meeting to provide feedback and finalize recommendations.

Next meetings:

Wednesday, February 15	3-5pm at 1 Ashburton Place (rescheduled from January 17)
Monday, March 6	1-3pm at DPH